

# *The Michigan FAS Web*



*"When spider webs unite they can tie up a lion."  
~African Proverb~*

## **Consensus on Terminology**

What do you call it when an individual has some but not all of the characteristics used to diagnose fetal alcohol syndrome? Well, some might say fetal alcohol effects (FAE), others alcohol related neuro-developmental disorder (ARND) or how about fetal alcohol related conditions (FARC). Still others might use alcohol related birth defects (ARBD) or prenatal exposure to alcohol (PEA). The latest term to be introduced is Fetal Alcohol Spectrum Disorders (FASD). Depending on who you talk to these terms mean different things. To some they are descriptive, to others diagnostic. Confusing—you bet!

Fortunately, a summit was recently hosted by the National Organization on Fetal Alcohol Syndrome (NOFAS) to produce a unanimous consensus on terminology related to prenatal exposure to alcohol.

Representatives from the Centers for Disease Control, National Institutes of Health, and Substance Abuse and Mental Health Services Administration came together to discuss their concerns over the confusion around what to call the broader effects of prenatal alcohol exposure when a diagnosis of Fetal Alcohol Syndrome cannot be made. Summit participants agreed

that it was important to have a term that communicates the range of issues surrounding Fetal Alcohol Syndrome. Their chief concern was for parents, families, and public policy officials to be able to speak with one voice when it comes to treatment and prevention related to prenatal exposure to alcohol.

The participants produced and signed a unanimous agreement on the use of the terminology for Fetal Alcohol Spectrum Disorders (FASD).

**~Summit Consensus Statement~**  
***Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis.***

According to summit co-chair Dr. José Cordero, Director of the National Center on Birth Defects and Developmental Disabilities. "Acceptance of this new terminology will go a long way

toward getting individuals with the wide range of Fetal Alcohol Spectrum Disorders the recognition, treatment, and services they need."

Please join in on promoting the use of this terminology to help raise awareness and understanding throughout the community that prenatal exposure to alcohol can result in a wide range of impairments, all of which are 100% preventable.

## What is EEG biofeedback?

According to the Biofeedback Certification Institute of America, "If you have ever taken your temperature or stepped on a scale to see how much you weigh, you have used biofeedback. The temperature and weight readings from these devices give 'feedback' about your body to tell you whether you have a fever or have gained weight." General biofeedback, using readings primarily from muscle tension and/or skin temperature, has been used for years to treat such disorders as hypertension, incontinence, headaches, chronic pain, and anxiety disorders. A lesser known version of biofeedback, EEG biofeedback, uses information from brain waves. These brain waves provide feedback on different mental states such as attention and concentration.

The Biofeedback Certification Institute of America explains that "Biofeedback is a non-invasive form of treatment. The therapist attaches sensors or electrodes to the body and these

sensors provide a variety of readings--*feedback*--which is displayed on the equipment for the patient to see. With this information, patients can learn to make changes so subtle that at first they cannot be consciously perceived. With practice, however, the new responses and behaviors can help to bring relief and improvement to a variety of disorders."



The goal of EEG Biofeedback training is to promote and diminish various brainwaves into a more "normal" pattern. Brainwave activity is shaped through auditory and visual rewards as the client sits passively looking at images on the computer monitor. The brain waves are being (subconsciously) trained toward a more desirable performance. This type of biofeedback appears to be helpful in treating ADD and ADHD, anxiety disorders, addiction and many other problems. It is also a promising new intervention for individuals affected by prenatal exposure to alcohol.

## What a Difference a Year Can Make

by Carol Cole

One year ago our family life was quite different than it is today. EEG Neurobiofeedback has really made a difference for my 9-year-old son, diagnosed with FASD. My son's out of control rages used to be an every-day event. I was developing a new understanding of what it meant to "pray constantly." An FAS Homeschoolers Newsgroup on the Internet became a significant source of support. I could listen and share, and I knew I was not alone. During this trauma my faith kept me hopeful, intuition guided my search, and desperation made me willing to take risks. When I discovered some information about EEG biofeedback on the FAS/FRI web site (<http://www.fetalalcoholsyndrome.org/anneeg.txt>), I was interested. With the encouragement of my son's pediatrician, I decided to try this "alternative" treatment with my son.

Over a six-month period last year, my son had just over 40 bi-weekly sessions. I have been very happy with the results so far. It is my hope that I will be able to afford another 40 sessions for him again this year. Here are some excerpts from my Newsgroup "diary" as I emailed my co-laboring

homeschool moms of the changes I saw in my son. Training began the first of April and I saw no noticeable changes until-

### Mid May:

➤ Sunday in church, DeAndre leaned over to me and said (in my ear) "Mom, I have three bad things to tell you after Mass." If you do not think that is amazing, you do not know my son. He had **whispered** (not a shouting sort of whisper), he did it **in my ear** (not in my face) and, most utterly amazing of all, he was going to tell me **AFTER MASS..... THREE THINGS**. A month ago, he could not have retained three things in his mind for even a second. And *now he is telling me that he is going to tell me these three things... not NOW, but later!* Would he really be able to remember them after Mass? During Mass he asked fairly reasonable questions, accepted "no" for an answer, and stopped what he was doing when I asked him to. No argument. No growling. No angry face. In the car on the way home, he **CALMLY** stated the three "bad things." I am amazed!

Sometime in late May I realized that the rages had completely stopped. They have never returned. During June and July vacation time interrupted the training for 3 weeks. Gradual changes were unremarkable, then in—

### Late July:

- Today we visited my brother and my son received a complicated Bionicle set as a gift. In the car on the way home he started working on putting this set together. Fairly soon, with heightened tension in voice, he was announcing that he had "goooooofed uuuuup" on his Bionicle. Then he said, "so I'm going to wait till another time..... maybe a time when there is an adult to help me." It was another one of those amazing and telling moments. The fact that he did not whine and moan with escalating volume as his control vanished was amazing enough. But, to remain calm AND to say he's going to wait for another time, when he can get help... Now THIS is something he has never been able to do. In fact, on a similar occasion at my brother's a year ago, things had played out quite differently. We had said our good-byes with hugs and all. Before the car was all the way out of the driveway, he was screaming, "I want to say goodbye one more time! Take me Back! Right now!" Before we were 6 houses down, he had begun hitting his little sister in her car seat, and both were screaming. This kind of scenario was not uncommon in those days.



eyed... "Mom, I can do it! I can make pancakes myself, for everybody! Can I? I can do it!" I was really pushing the envelope to tell him that he must do it without my help and to clean up as well. I am writing to tell you that he actually did it. He did it without my help.. Without any questions, without any moaning, without any crisis. The only thing I did was to adjust the (gas) heat under the pan to the right height. He served it. He cleaned it up. The amazing thing is that he did all this on NO MEDS. He waited to take meds until after he had eaten. A year ago in the mornings, I was checking my watch from the moment he got up counting the 45 minutes until life, for all of us, would be a little less volatile and less violent.

Now in April, one year after starting my son on EEG, I find myself less dependent on the newsgroup for my only support. I get out more. I can attend social events with my kids and not worry about what my son might do. It has taken me some time to stop over-reacting in situations that had typically been problematic. I have calmed down quite a bit. Early mornings and evenings are much more reasonable. Instead of violent rages at the end of the day, he is simply irritable, unfocused, and has a harder time controlling his emotions. This year of homeschooling has been much more enjoyable. He is progressing slowing and is accomplishing the basics of a curriculum about one year behind others his age. He still has trouble with retaining math facts, needing to learn and relearn. He remembers best with a song. Academics are tough, but he has not had one day in which he could not pull himself together when things got tough. Emotionally, he is much more "even keel." He is an easier student to work with.

Anyone interested in learning more about EEG neurobiofeedback can uncover a variety of information by doing a web search on the topic. I have found the eegspectrum.com site to have information and links to a variety of sites. There are many types and varieties of equipment, effectiveness, and use among practitioners in this as yet largely unresearched field. Many sites contain a variety of testimonials and studies. I am not aware of any studies that have been done at major research universities to date. It is my hope to secure funding for further trials using neurobiofeedback for individuals with FAS/E with the intent of laying the groundwork for further study.

EEG had been training his brain to be less impulsive. My son has certainly become less impulsive. He hits and grabs less often, lets go sooner, and recovers more quickly. An additional "side effect" for my son seems to be that he is able to "think" more clearly. We say that with FAS, there is no cause and effect thinking. This is why kids continually do what they know they are not supposed to do. It seems that his brain is somewhat more able to kind of think things through on a regular basis. I decided, with the pediatrician, to reduce my son's medication.

### In October

- This Saturday when I said "no pancakes" at breakfast time I was half expecting a major melt down. A year ago this would have set my son in a downward spiral from which he might not have recovered all day. Instead, after he started to moan, he turned back and appeared very bright

## *Support for Families in the Livingston County Area*

Families with children who have special needs can find support and education at the Livingston Educational Service Agency on the 4th Tuesday of the month from 7:00—9:00 PM. A group meets monthly to hear speakers on a variety of topics including advocacy, self-determination, health issues, therapies, school issues and the like.

For more information, contact Kathy Maher at [kmaher2@sbcglobal.net](mailto:kmaher2@sbcglobal.net) or call (517) 546-8825.

## **DON'T MISS OUT...**

### **Fetal Alcohol Spectrum Disorders (FASD): Best Practices in Prevention and Intervention**

- ♦ August 18 & 19, 2004
- ♦ Muskegon, Michigan
- ♦ For more information, contact Sarah at (616) 336-4940 or [sarah.bobo@kentcounty.org](mailto:sarah.bobo@kentcounty.org)

### **Being our Best with FAS: A Conference By and For Individuals with FASD**

- ♦ August 19—22, 2004
- ♦ Camp Henry—Newaygo, Michigan
- ♦ For more information, contact JoCindee at (231) 883-1088 or [jcsurya@aol.com](mailto:jcsurya@aol.com)

### **Check Out these Great Internet Resources**

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| ♦ Michigan Department of Community Health's FAS Page<br><a href="http://www.michigan.gov/fas">www.michigan.gov/fas</a>  | ♦ FASD and the criminal justice system<br><a href="http://www.asantecentre.org">www.asantecentre.org</a>           |
| ♦ FASD Tool Kit from the Canadian Centre on Substance Abuse<br><a href="http://www.ccsa.ca/toolkit/introduction.htm">www.ccsa.ca/toolkit/introduction.htm</a> | ♦ Summer camps for children with special needs<br><a href="http://www.ccrea.org">www.ccrea.org</a>                 |
|   | ♦ Fen Pen newsletter<br><a href="http://www.fammed.wisc.edu/fen/fenpen.htm">www.fammed.wisc.edu/fen/fenpen.htm</a> |

**Michigan FAS Web Newsletter**  
c/o Kent County Health Department  
700 Fuller NE  
Grand Rapids, MI 49503